

NPM #6: The percentage of youth with special health care needs who received the services necessary to make transition to all aspects of adult life. (CSHCN Survey)

Impact on National Outcome Measures: Data from SLAITS indicate that only 7.4 % of Wisconsin youth with special health care needs report that they are receiving services necessary to make transitions to adult life.

a) Report of 2003 Major Activities

1. Partnership between CSHCN Program and Healthy and Ready to Work (HRTW) designee—Infrastructure Building Services—CSHCN

The Waisman Center, one of five Title V funded Regional CSHCN Centers successfully applied for HRTW grant as Wisconsin's CSHCN Program designee. The Waisman Center uses the same 800 number for CSHCN Center and Transitions I&R Hotline. The CSHCN Centers identified a transition liaison for HRTW activities and participated in the HRTW Statewide Interagency Transition Consortium. The CSHCN Program and Waisman HRTW collaborated on designing transition questions for SPHERE, the MCH data system. Although SPHERE was not fully operational, HRTW Project was able to hand collect data from all CSHCN Centers indicating that, in 2003, 258 YSHCNs received transition information and/or training.

2. Healthy and Ready to Work Outreach—Population-Based Services—CSHCN

The CSHCN Program co-sponsored Circles of Life Conference for parents and providers. The HRTW project funded a concurrent session for the Gathering of Youth. Calls to the FirstStep hotline with questions on YSHCN transition resources or procedures were referred to HRTW hotline and website. The HRTW also coordinates a Wisconsin transition listserve.

3. Healthy and Ready to Work Training—Infrastructure Building Services—CSHCN

The HRTW program and CSHCN Centers conducted trainings for High School students and teachers about Transition IEPs. The HRTW provided workshops to parents/providers on how to support youth in their health care decision making. The CSHCN Program, HRTW, Social Security Administration (SSA), state Division of Vocational Rehabilitation (DVR) and Department of Public Instruction (DPI) conducted a series of video conferences.

4. State Partnership Building—Infrastructure Building Services—CSHCN

The CSHCN Program participated in the Medical Home Learning Collaborative, and HRTW provided pediatric practices with expertise and insights while learning what information is needed by doctors to assist YSHCN in transitioning to adult providers. The HRTW and SSA designed a streamlined SSI application process for youth aging out of WI "Katie Beckett" Medicaid waiver. The CSHCN participated on WI TBI Advisory Board and assisted with MCHB TBI grant application. The HRTW presented on how to prevent sexual abuse/exploitation of disabled youth at state teen pregnancy prevention/intervention conference. The CSHCN Program designated Waisman Center HRTW Project as state applicant for a Champions for Progress Incentive Grant to "jump start" its Youth on Health initiative designed to learn from youth what they need for successful transitioning. Youth on Health will serve as the foundation of a permanent Title V CSHCN Youth Advisory Council.

b) Current 2004 Activities

1. Partnership between CSHCN Program and Healthy and Ready to Work (HRTW) designee—Infrastructure Building Services—CSHCN

CSHCN Program and Waisman will continue most activities previously described.

2. Healthy and Ready to Work Outreach—Infrastructure Building Services and Outreach-Population-Based Services—CSHCN

The CSHCN Centers are documenting transition services they provide as well as needs that go unmet. Each Regional Center is providing at least one transition training for youth, parents, and/or service providers. In Southeast Region, HRTW is hiring community connectors to provide more in-depth applications of person-centered life planning and asset based community development models for Latino communities. HRTW, DPI, & DVR provide funding and resources for week-long "Transition Camp" to provide disabled teens an opportunity to be away from home, with peers have fun and learn about transitioning. DPIs SIG/Transition dollars are funding four 8-week courses that teach teens and adults with disabilities personal safety at home, work, and in public.

3. State Partnership Building—Infrastructure Building Services—CSHCN

SPHERE will be in operation enabling the Program to establish baseline for NPM#6 and track progress. Additional pediatric practices are participating in state funded Medical Home expansion with HRTW providing TA as requested. SSA is piloting the new streamlined SSI application for youth aging out of "Katie Becket Waiver" eligibility. Champions for Progress Incentive Grant is funding CSHCN and HRTW partnership in the Youth on Health process, organized and facilitated by HRTW, using three YSHCN focus groups to gain input on status of NPM#6.

c) 2005 Plan/Application

1. State Partnership Building—Infrastructure Building Services—CSHCN

The HRTW is funded until June 30, 2005 with many 2003 and 2004 HRTW and CSHCN Program activities continuing. Information obtained from the YSHCN focus groups will be used in WI five year Title V needs assessment and Block Grant application. Youth on Health focus group members come from Wisconsin Leadership Forum, HRTW Project Youth Advisory Board, or they attended the 2004 Transition Camp. After the focus groups conclude, they will be invited to participate on new Wisconsin YSHCN Advisory Council, organized to provide CSHCN Program with ongoing youth perspectives. The Council may also be asked to comment on other public health initiatives targeted toward youth. In its final year, HRTW will evaluate the impact of its activities. Results will be valuable to the CSHCN Program in planning future services. The Transition Consortium has begun to strategize about alternative funding to sustain activities when HRTW grant ends.

2. Healthy and Ready to Work Training—Infrastructure Building Services and Outreach-Population-Based Services—CSHCN

The CSHCN Program, HRTW, and Consortium members will continue collaborating with families, youth and other transition stakeholders in training and public awareness activities; planning and service design. Some

issues include beginning as early as middle school: person-centered life and vocation planning; accessing quality, person-centered health care and other community based services; impacts of chronic illness and disability on all aspects of human growth and development.